Title: 'Do you mean I'm not whole?': Exploring the role of support in women's experiences of mastectomy without reconstruction.

Running title: The role of support in women's experiences of mastectomy

Abstract

This study explores the role of others in supporting younger women who opt not to reconstruct their breast post-mastectomy. Semi-structured interviews were conducted with six women, diagnosed with breast cancer in their 30s/40s. The women lived in England, had been diagnosed a minimum of 5 years previously and had undergone unilateral mastectomy. An interpretative phenomenological analysis revealed three themes; Assuring the self: "I'll love you whatever", Challenging the self: 'Do you mean I'm not whole?', and Accepting the self: 'I've come out the other side'. The women's experiences of positive support and challenges to their sense of self are discussed.

Key words: Interpretative phenomenological analysis, reconstruction, breast cancer, mastectomy, support

‘Do you mean I’m not whole?’: Exploring the navigation of self in women’s experiences of mastectomy without reconstruction.

Introduction

Of the fifty thousand women diagnosed with breast cancer in the UK per year, 20% are under the age of 50 (Cancer Research UK, 2013) and 90% of these younger women have breast conserving surgery or mastectomy as part of their treatment (Lawrence, Kearins, Lagord, Cheung, Sidhu and Sagar, 2011). Following mastectomy, immediate or delayed breast reconstruction (IBR/DBR) is routinely considered (Morrow et al., 2009; NICE, 2009); it is positioned in the medical literature as being surgically optimal (Fang, Shu and Chang, 2013; Crompvoets, 2006; Schmauss, Machens and Harder, 2016) and beneficial for psychological adjustment, especially for younger women (Roje, Roje, Jankovic and Ninkovic, 2010; Wilkins et al., 2000). Previous literature has heralded the benefits of breast reconstruction (BR) including improved self-esteem, sexuality and body image (Wilkins et al., 2000; Ananian et al., 2004). Other studies have concluded that differences in body satisfaction and psychosocial outcomes in women who do and do not reconstruct their breast(s) are not significant over time (Rowland et al., 2000; Metcalfe et al., 2012). A recent longitudinal study in Canadian women showed women who had DBR reported significantly higher levels of obsessiveness and cancer-related distress compared with those with mastectomy alone; no differences in quality of life were evident between the groups over time (Metcalfe et al., 2015).

Statistics delineating reconstruction rates by age are not readily available in the UK, but data from the US indicate that BR rates are increasing and younger women are more likely to select reconstruction (Jagsi et al., 2014). However, across all known epidemiological studies, uptake is less than 50%, suggesting that despite the assumed psychological benefits, the majority of women worldwide do not reconstruct post-mastectomy (Alderman, McMahon and Wilkins, 2003; Abu-Nab and Grunfield, 2007; Morrow et al, 2009). A recent systematic review showed that international BR rates range from 4.9% to 81.2% (Brennan & Spillane, 2013). Previous country-specific reports have indicated low BR uptake (under 20%) even in Western countries including Australia (Wong, Snook, Brennan, Flitcroft, Tucker, Hiercz et al, 2014), Denmark (Hvilsom, Homich, Steding-Jessen, Friis and Dalton, 2011) and England (Jeevan, Cromwell and Browne, 2010). It has been posited that rates increase when more BR

information is offered to patients (Wong et al, 2014) and that BR options should be discussed in all consultations post-BC diagnosis (NICE, 2009).

Mastectomy is still commonly associated with lowered self-esteem (Al-Ghazal et al., 2000), stigma (Fang et al, 2013) and changed relationships with others (Loaring et al., 2015). It also disrupts the norm of being a two-breasted woman. Post-mastectomy bodies are perceived to be unnatural, incomplete and are stigmatised (Fang et al, 2013). It is not surprising that some women who undergo mastectomy experience a challenge to their femininity (Kasper and Ferguson, 2000; Hallowell, 2000), body image (Fobair, Stewart, Chang, D'onofrio, Banks and Bloom, 2006; Grogan and Mechan, 2016) and sexuality (Rowland et al., 2000, Emilee, Ussher and Perz, 2010; Markopoulos et al., 2009). Some Western breast cancer survivors, who have not pursued BR post-mastectomy, describe themselves as "half a woman" (Manderson and Stirling, 2000, p.82) and say that the loss of their breast "shattered" their identity (Fallbjörk et al., 2012, p.45). It is important, however, to acknowledge that some breast cancer survivors report the loss of their breast(s) as "no big deal" and appear to cope well with their body image re-appraisal (Fallbjörk et al., 2012, p.41).

The perceived level of social support offered by others has been associated with improved psychological adjustment for women with breast cancer (Maly, Umezawa, Leake and Silliman, 2005; Kinsinger, Laurenceau, Carver and Antoni, 2011). It may even enhance survival (Bloom, Stewart, Johnston, Banks and Fobair, 2001). Specific characteristics of support experienced and valued by cancer patients include emotional support (empathy, validation and assurance), informational support (giving advice and information) and instrumental support (functional assistance with daily tasks) (Helgeson and Cohen, 1996). Partners, family, children, friends and healthcare practitioners all play important supporting roles for women with breast cancer as they navigate their diagnosis and treatment, and adjust to their post-cancer lives (Brothers and Andersen, 2009; Friedman et al., 2006; Weihs, Enright and Simmens, 2008; Arora, Finney Rutten, Gustafson, Moser and Hawkins, 2007; Zhou et al., 2010).

To date, it appears that there has been no research studying the role of others on the lived experience of younger women who have navigated breast cancer treatment and opted not to pursue BR after mastectomy. To address this gap, the aim of this study is to explore the

lived experience of support and challenge encountered by women in their familial and social settings and to interpret the impact of this on their sense of self. Within this paper, we explore the experiences of a sample of British women diagnosed in their 30s/40s and analyse their perceptions of support.

Methods

Participants were recruited though an online UK breast cancer forum: the second author posted a recruitment call and participants contacted her directly. Semi-structured interviews via Skype (audio only) were conducted with six younger women who had been diagnosed with primary breast cancer a minimum of five years previously. The median age at diagnosis was 38 years (range 31-46) and all were living and treated in England within the National Health Service (NHS). Five of the women were married or partnered at diagnosis and four disclosed their motherhood status: three stated they had children and one was pregnant when diagnosed (Table 1). None were eligible/recommended to undertake IBR after their mastectomy and decided not to take up DBR when it became available. The study conformed to the British Psychological Society's (BPS, 2009) ethical standards and the University's psychology ethics committee granted approval. Participants gave full and informed consent and received a £20 shopping voucher for their participation.

** Table 1 around here**

Interviews (lasting between 30 and 60 minutes) were audio- rather than video-recorded via a laptop through Skype™. Each interview followed an open-ended schedule and focused on the women's lived experience and their decision not to reconstruct at any point post-mastectomy. They were asked to reflect on how their treatment affected relationships with partners, familial and social others. Recordings were transcribed verbatim and pseudonyms were used throughout.

Transcripts were analysed using Interpretative Phenomenological Analysis (IPA), an approach widely used in health psychology over the past two decades (Smith, Flowers and Larkin, 2009; Smith, 1996), with many pieces of high quality research focusing on illness experience (Smith, 2011). Breast cancer experiences have been explored using IPA in the US (Vilhauer, 2011; McDonough, Sabiston and Ullrich-French, 2011), the Netherlands (de Boer, van der Hulst and Slatman, 2015), and in the UK (redacted for review; Loaring et al., 2015).

Data Analysis

Three themes are discussed here: Assuring the self: "I'll love you whatever", Challenging the self: 'Do you mean I'm not whole?', and Accepting the self: 'I've come out the other side'. The decision-making process of the same participants has been explored in depth previously (redacted for review). In short, the women's reasons for non-reconstruction included a reluctance to undertake more surgery accompanied by the hassle and healing this would entail. Additionally, some perceived DBR as not being a positive choice for them. Many valued the stability they had achieved in their lives without this. Some perceived that BR would prevent early detection should breast cancer recur. The participants all recognised this was an informed choice and they all cited gratitude for survival that outweighed their need for BR.

Theme one - Assuring the self: "I'll love you whatever";

For the majority of the women, their close relationships with male partners, parents and friends provided them with unconditional support. As the women negotiated their diagnoses and their new identities, these relationships offered them a safe space for navigating a physically and emotionally traumatic time in their lives. Most of the male partners at the point of diagnosis were consistently supportive throughout the women's accounts of all stages of the experience. Paula summarised this unconditional support common to these women:

> His attitude was that it [the decision to pursue BR or not] was entirely up to you, he was very much "it doesn't matter to me", particularly at that point it was it was more about survival more than anything else, it very much changes your perspective on things. He was very much "you'll still be the same person and I'll love you whatever" so for me it was quite reassuring.

This type of support was evident throughout these women's accounts of their recovery, providing a consistent frame of reference over a time of significant upheaval. Maureen's husband offered a positive lens through which to view her mastectomy scar:

> My husband always says to me “it doesn’t matter because due to that flat bit you’re still here” and that is the bottom line isn’t it really?

Adjustment processes were facilitated by this unconditional support: Sarah reported surprise at how quickly both she and her partner adjusted to her post-mastectomy body. Maureen described how her close family support was highly valued, reliable and ‘sincere’. Her parents and husband were relieved that she was not pursuing BR. She perceived this to be a consistent view within her wider social circle:

> I think everyone else respected my decision [to not reconstruct her breast], nobody said oh, that’s really stupid, why aren’t you having it done so that was, again, that gave me a bit of confidence in not having it done.

This direct and indirect support played a role in bolstering the women’s fledgling identities as one-breasted women. Maureen’s perception highlighted that her decision was potentially open to challenge from others, which may have led to her questioning her decision to forgo BR. This points to the fragility of the sense of agency at this time.

Other participants noted the importance of having an extended social circle which ‘helped [them] get through it’ (Paula). Specifically, Anya, the one participant who was un-partnered throughout her breast cancer experience sought tangible, pragmatic support from friends:

> I had a lot of support from friends actually, they used to have her [her daughter] for the weekends after I was recovering from the chemo.

This support was particularly important for Anya, who reported lacking an effective family network and subsequently did not receive the unconditional support that was so profoundly reassuring to the other participants. Her interview was distinctly different in terms of the levels of emotional support reportedly available to her. She was a ‘lone parent’ and this

sense of aloneness and isolation was evident throughout her transcript as she sought to support herself and her daughter through the experience.

This theme highlights the important function of unconditional support from partners, close family and friends, which moderated the emotional and physical impact of the women's breast cancer experience. The experience reported by the women who lacked this support was less positive, more emotionally turbulent and led to a longer adjustment period.

Theme two - Challenging the self: 'Do you mean I'm not whole?'

As the women began exploring the acceptability of their post-mastectomy bodies in wider social contexts, they encountered situations that challenged their emergent identities and developing sense of agency. When intimate others discounted the acceptability of their actions the effect was dramatic. Eloise recalled her first husband's [they later divorced and she re-married] night out with workmates that occurred while she was recovering from her mastectomy:

> They went to a lap-dancing club and I remember at the time being furious with him for going, because I said to him, how dare you go and look at somebody who is, who's normal, who's got two [breasts], you know, how do you think that makes me feel?

Her vulnerability as a self-described newly 'mutilated' woman, questioning her femininity, is clear in her description of her sense of betrayal. This foregrounds the crucial nature of the unconditional support evidenced in other women's accounts in the previous theme. Here, Eloise implied her feelings of otherness and inferiority in relation to the women in the lap-dancing club: her husband's actions threatened her sense of self as an attractive, sexual woman. He is reportedly oblivious to her emotional needs which speaks to a lack of regard for her feelings at this sensitive time.

A lack of emotional connection was also present in Anya's account; however, this related to her experience of showing her mastectomy scar to her mother:

> I have a very, very, kind of distant relationship with my mother anyway and she just said to me, "ooh, that looks sore" [Anya

> laughs] I thought, well if that's all you can come out with, I, so I didn't really get any kind of cuddles or spectacular reaction from her.

From Anya's perspective her mother does not provide the necessary response that she is desperately seeking. Her sense of longing is demonstrated through her use of the word 'cuddles', alluding to a childlike state, seeking unconditional comfort and nurturance. Anya's suggestion of her mother's lack of emotional reaction speaks to her lonely cancer experience. In turning to a close male friend for the support lacking elsewhere Anya continued to find her emotional needs unmet:

> I think his reaction [to seeing her mastectomy scar], I mean he kind of put a brave face on [Anya laughs], but I think he was a bit shocked to be honest.

Her perception of his response revealed that what she was searching for – a heartfelt recognition of her experience – was clearly not available from this particular friend. The language Anya used to describe these interactions suggests the understatement of emotion and lack of warmth that she encountered. Conversely Sarah felt supported by male friends who offered a less emotional reaction:

> It is a more difficult thing to talk to female family or friends about than it is to talk with men who tend to be more pragmatic.

Sarah's female counterparts struggled to support her decision to remain one-breasted after surgery, which she interpreted as being because they had 'the same body parts' and identified more closely with the potential for breast cancer and breast loss. She suggested that they could not hear her story without locating themselves as the protagonists in it 'oh gosh if it was me'. In comparison, her male friends considered the non-BR decision as 'fair enough'; a response which she found more comforting and sincere.

Some of the women referred to instances where their experience was assumed by others to be negative. These included cancer related settings where they might have expected to

receive a greater level of acceptance based on their shared experience with other breast cancer survivors. Paula recalled:

> I had a lady once, I met her when I had my radiotherapy, who asked me "how are you coping with your disability?" And I'm like "what? What do you mean?" And she said "you had a mastectomy" and I said "that is not a disability" and she said "well I think it is."

Paula has a sense of self as being whole and this challenge from another woman who was going through a similar experience suggests a 'weird attitude'. This fellow patient's reported view revealed connotations of stigma, which Paula had discounted as being part of her identity as a one-breasted cancer survivor. Similarly, Rebecca encountered negativity around her choice of non-BR at a young survivors' event hosted by a cancer charity. The guest speaker, a survivor and well-known British pop star, was reportedly pro-BR in her keynote address:

> [She] was just like "well you must have reconstruction, it will help you, it make you feel like you're whole again," la di dah [Rebecca laughs] and while I was sitting there I thought well, do you mean I'm not whole? It made me feel really quite awkward.

Rebecca had felt comfortable and well supported in her decision prior to this point. Her interpretation of this challenge to her sense of wholeness positioned her as part of an out-group: she perceived that she was going against a norm that valued younger, feminine women as having two breasts. Consequently, she disengaged from the group discussion that followed which proposed BR as the only 'acceptable route' which was 'quite shocking' and which discounted her experience and decision as being valid.

Sarah also recounted encountering divisive messages from other women in a setting offering breast cancer support. In one particular discussion of their post-mastectomy bodies, she perceived insensitivity to her decision to not pursue BR from others who had chosen that route. One of the women was reported as saying 'I thought my scar was hideous' and 'I was so misshapen' prior to having BR. Sarah's reaction to these negative attitudes was also to withdraw:

> I just smile and nod, but I do find that quite hard, it's almost as though we're divided into two armed camps, really.

Rather than voicing her hurt in relation to the perceived criticism from this woman that she reported as 'blunt and brutal', Sarah actively held back her own feelings. In doing so she respected the other woman's experience, even though she felt disrespected and offended by the woman's lack of acceptance of her alternative decision.

In summary, this theme demonstrates that participants experienced a range of challenges, often unexpectedly and from a variety of sources. For the women who had had the assurance of unconditional support from their closest relationships, these encounters came as a shock and were difficult to navigate. Although their confidence in their decision not to pursue BR was maintained, they indicated a feeling of exclusion from the wider breast cancer community through their narratives.

Theme three - Accepting the self: 'I've come out the other side'

Across the dataset the participants described how their experiences over time led them to a place of greater self-acceptance. Through receiving the support and navigating the challenges presented by others, the women moved beyond the initial phases of their cancer experience that seemed to be all consuming. They re-engaged with the wider world, where being a breast cancer patient was no longer their main identity. The sense of a new normal was clearly evidenced throughout the transcripts. The language used by the women to report their later experiences revealed more positive messages. Paula said:

> it's just become part of our lives if you like, it's nothing sort of different or amazing, it's just something that you know my daughter says "my mum's only got one boob", you know so I think it's just sort of normal for us now.

Here, the unquestioning acceptance of Paula's mastectomy by her daughter was a product of Paula being 'open about it' with her and not making 'a big issue' throughout the treatment and recovery process. This approach reaped rewards, as Paula's own self-

acceptance was facilitated by this open discussion leading to a feeling of normality for them as a family. The term 'one boob' suggests a lack of stigma in the way that Paula's daughter constructed her mother's experience.

Similarly, Rebecca described the normalisation of her altered body within the family context. She reported her son as playing with her 'prosthetic boob' and it not being 'hidden'. She also adopted this open approach in broader social settings, such as a changing room:

> I can see it [her mastectomy scar] as a war wound, it's something that has happened and if anything, if somebody sees it they can see yes I've had breast cancer and I'm still here and it's alright.

Rebecca positioned herself as a proud survivor of a disease that waged war on her body. Her scar was seen as symbolic of her cancer story in which she is the living proof of a happy ending. This visible evidence of her difference, demonstrated her lack of embarrassment about her body and her resilience and pride was clearly stated. A similar image was offered to Anya as a symbol of her experience by a male friend. He described her mastectomy scar as a 'badge of courage' which she said made her 'feel good' about herself. As someone who had had very little emotional support from others, this acknowledgement of her 'stoicism' boosted her self-belief and led to her greater self-acceptance.

Some participants sought out opportunities to educate others about their experiences. For example, Eloise used interactions with co-workers to openly share information:

> It doesn't bother me at all, I whip out my prosthesis and say, "no, this is what's in there" and they say, "can I touch it, can I feel it, ooh can I hold it" and things like this, because I don't see the point in being embarrassed about it and I'm really quite proud of it as well.

Eloise took the opportunity to challenge her co-workers' potential prejudice by showing them exactly what a prosthesis was like. They were framed as people who had no knowledge of her breast cancer treatment. She revealed her identity as a breast cancer survivor who chose not to reconstruct her breast and this was used as a teachable moment

in which to show the positives of this decision. This experience clearly showed Eloise as the expert: she held the power in this interaction, in contrast to the powerlessness she discussed in other parts of her interview, such as when talking about her problematic relationship with her husband. She also discussed taking this role with others in the face of a cancer diagnosis 'I showed my friend [her mastectomy scar] and I actually showed her husband as well'. She reciprocated the role of supportive other, demonstrating what her scar looked like. This was an opportunity she had been given by someone when she was diagnosed, and a role she was now in a position to take on. Different from her own case, however, the friend's husband was also included in Eloise's sharing of her scar.

Similarly, for Rebecca, offering a balanced viewpoint around post-mastectomy choices became a self-driven responsibility. She gained agency and found her voice in a situation similar to one in which she previously felt muted. At a breast cancer charity fashion show Rebecca encountered another young woman who was about to go through DBR but was worried about it:

> And so I had a quite a bit of dialogue with her about, I didn't put her off having it done, but to make her think well, why, what is the key purpose for her needing to have the reconstruction

Here Rebecca acted as facilitator for a discussion about the pros and cons of BR. She acknowledged the need for both decisions to be equally considered. She continued:

> Thankfully, a number of other models chipped in that they'd had the reconstructions and they were all right and so she got a balanced view of it

Rebecca demonstrated her awareness of the importance of creating a supportive environment in which this young woman could hear about and discuss a variety of options. This contrasts with the 'two armed camps' experienced by Sarah in her support group; Rebecca actively requested input from others who had BR which provided the woman with information and awareness, not judgement. Rebecca sought to improve another's experience, to protect the young woman from the stigma and isolation, which she had perceived in previous breast cancer support settings.

Within this theme, it is clear that several of the participants have come 'full circle'. They reflect on their more recent interactions with others and describe their appraisals of themselves positively. Their language suggests increasing acceptance, less challenge and greater personal growth. This contributes to a narrative of triumph over adversity.

Discussion

This analysis has revealed the importance of unconditional support from a variety of sources for younger UK-based breast cancer patients who chose not to reconstruct post-mastectomy and who maintained this decision over time. It also highlights the challenges that women face when negotiating other people's reactions and assumptions about their lived experiences. Finally, the women's resilience and acceptance of themselves and their situations are explored. These themes demonstrate the temporal nature of the women's experiences particularly surrounding self and social identity when navigating mastectomy without delayed BR.

Partners, family members and close friends all played an important role during the women's adjustment post-cancer treatment, which is consistent with other studies (Alferi et al., 2001; Brothers et al., 2009; Friedman et al., 2006; Weihs et al., 2008; Arora et al., 2007). The women who described high levels of partner support experienced a smoother and expedited adjustment, particularly within intimate contexts. This supports earlier research that linked positive partner support with greater relationship satisfaction in women with breast cancer (Brothers et al., 2009; Figueiredo et al., 2004; Boeding et al., 2014), and is consistent with other research exploring couples' experiences of negotiating intimacy after mastectomy and BR (Loaring et al., 2015). Our participants reported greater confidence in navigating and accepting their changed bodies when in receipt of support from intimate partners. In situations where this unconditional emotional support was perceived to be lacking, body confidence was undermined; the women felt insecure about their post-mastectomy bodies, and their identities were unstable. These differences in identity construction have been found in other breast cancer patients: previous studies have reported women without BR post-mastectomy as perceiving themselves as 'half a woman' (Manderson and Stirling, 2000,

p.82) or to have experienced a 'wounded' (p.E45) sense of femininity, while others perceived their breast loss as being less problematic (Fallbjork et al., 2012).

Interactions with others were not always perceived as being positive or helpful by the women. The idiographic nature of our analysis reveals the complexity and nuanced nature of other people's responses and how they were received. In several cases, the participants felt challenged by the reactions of others, an area little covered in the extant literature. In some cases, friends offered positive, functional and instrumental support. Male friends were reported as pragmatic while some female friends and acquaintances found an objective and supportive stance difficult to maintain when responding to the women's disclosures. Previous findings suggest that support promoting emotion-focused coping is offered by all friends (Arora et al., 2007); our analysis suggests that this is not always the case.

Support groups have been shown to offer cancer patients significant emotional support (Paul et al., 2014; Gray, Fitch, Davis and Phillips, 1997; Helgeson, Cohen, Schukz and Yasko, 2000); in our analysis these groups were not always presented positively and discussions around BR between women who had made different choices were sometimes emotionally charged and problematic. This has implications for support group facilitators. Additionally, breast cancer charities have been described as offering a useful resource for breast cancer patients (Grogan and Mechan, 2016). In our analysis, the messages reportedly given by such organisations may not have always offered a balanced view about BR for younger breast cancer patients.

Previously literature has identified the positive psychosocial outcomes for women who pursued BR, offering them a way of looking a feeling normal in previously stigmatized (Fang et al, 2013), deformed (Roje et al, 2010) and scarred bodies (Harcourt and Frith, 2008). The complexity of body image negotiation with women who have opted for BR has been documented (Crompvoets, 2006; Reaby et al, 1994, Rubino et al, 2007; Fallbjork et al, 2012; Metcalfe et al, 2015; Grogan and Mechan, 2016); however, very little to date has highlighted the experiences of women who opt not to pursue IBR or DBR (Authors, 2014). In their study with younger women with and without BR post-mastectomy, Grogan and Mechan (2016) found that positive framing of scars and rejection of Western beauty ideals was instrumental to the increased self-efficacy of some of their participants. They acknowledged the variability in the women's experiences and called for a greater focus on the individual

experience. Our analysis offers this idiographic approach with a sample of younger women who maintained their decision not to pursue BR. In our study, all of the participants reach a place where they accept their body without pursuing BR. This adds the experience of this specific sample to the wider body of literature.

In considering how our participants use their experiences with breast cancer to offer support to others, we can draw upon the literature around post-traumatic growth (Tedeschi, Park and Calhoun, 1998). In their actions we can interpret that all of the women had a positive change in identity and all spoke of the benefits they had gained from their breast cancer experience. Specifically, in their offer of informational advice (by showing their scars to educate), some of the participants offered vicarious experiences to others diagnosed with cancer. Participating in activities with other cancer patients can promote post-traumatic growth (Hefferon, Grealy and Mutie, 2008; Morris and Sahkespeare-Finch, 2011; Sabiston, McDonough and Crocker, 2007); our participants had been challenged in these situations. In reaching out and offering others a more positive experience, they can be seen to offer opportunities for post-traumatic growth. Outside of the cancer community, one participant's experience with her co-workers highlighted the positive use of her identity as a breast cancer survivor; she became an advocate for educating them about breast cancer and non-BR. This adds to the cancer literature, which lacks an understanding of the role of co-workers (Taskila, Lindbohm, Martikainen, Lehto, Hakanen and Hietanen, 2006); this individual's experience suggests that post-traumatic growth may also develop in the workplace.

Our analysis adds to the existing literature by introducing a British perspective; however, limitations should be acknowledged. The sample size is small yet consistent with the IPA approach. Women's age, sexual orientation, and relationship status should be considered in future research. In line with most previous research, the study reported here is retrospective in nature: women were interviewed at least five years post-diagnosis. They therefore had adjusted and reflected upon their situations and their recollections had been shaped by time. Partners and other sources of support for the participants were not interviewed, thus the reflections of their support were those of the participants only. Further studies exploring the lived experience of women who remain as one-breasted or no-breasted post-mastectomy would be valuable. Dyadic studies incorporating the perspective of significant others may also contribute to the understanding of the phenomena of support during breast

cancer treatment and recovery. Further explorations into cancer patients' experiences of negotiating their re-entry into the wider worlds of work and social contexts would also add to the existing cancer literature as little known about this for women across the lifespan.

From our analysis, several recommendations for practitioners arise. Initially, a holistic needs assessment conducted by a breast cancer nurse would help to identify types of support available (or not) to the patient. This could offer an important opportunity for signposting women to appropriate resources. Social support offered (e.g. support groups; breast cancer events) need to be facilitated carefully to enable all women's choices and experiences to be equally acknowledged and validated. The importance of acceptance by partners' was highlighted, and speaks to the ongoing need for them, or others who take on this role, to be effectively informed and supported. Access to more even-handed information about maintaining a mastectomy without BR was recommended by all the participants in our study.

Conclusion

For our participants, the decision to not reconstruct was maintained over time. Various types of support, from a range of people, were offered to the women during their diagnosis, treatment and recovery; this was mostly positive. In some circumstances the women's decision around non-BR was challenged (directly and indirectly) which challenged their identities and was, in some cases, emotionally distressing. All of the participants reported reaching a more accepting view of themselves; this was a product of the support provided by others, the forging of their new sense of self, and the successful navigation of challenges over time.

Declarations of conflicting interests

None declared

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